

EXHIBIT C

MINUTES

LEGISLATIVE TASK FORCE ON SICKLE CELL DISEASE

Meeting

Wednesday, September 2, 2015

The Legislative Task Force on Sickle Cell Disease met on Wednesday, September 2, 2015, at 10:30 a.m., in Room 138 of the State Capitol, in Little Rock, Arkansas.

Members in Attendance

The following members attended: Senator Stephanie Flowers, Chair. Non-legislative members: Dr. Rhonda Mattox, Ms. Angela Mull, Ms. Michelle Murtha, Ms. Patricia Purifoy and Dr. Suzanne Saccente.

Opening Remarks

Senator Flowers called the meeting to order and recognized task force members for introductions. Each member introduced themselves and briefly explained where they worked. Senator Flowers announced that the task force will expire on October 1, 2015.

After a brief discussion, the task force agreed to continue meeting on a quarterly basis as a work group after the expiration date.

The following audience members were also recognized for introductions. **Ms. Tina Benton, Program Director, ANGELS, University of Arkansas Medical Sciences and Oversight Director, Center for Distance Health (UAMS), and Ms. Donna Richardson, Registered Nurse, UAMS.** Ms. Benton said she is representing the sickle cell project that is funded through ANGELS, noting that ANGELS is the core base of several telemedicine activities in Arkansas. Ms. Richardson said she is the project manager for the adult sickle cell clinic. **Mr. Curtis Johnson**, brother of the late Mr. Germaine Johnson, former chairman of the Task Force, was also recognized.

Consideration to approve Minutes of October 3, 2012 [EXHIBIT C]

By acclamation of the task force and without objection, the minutes were approved.

Discuss Task Force Goals and Objectives

After a lengthy discussion, the task force discussed future goals, objectives and ideas that included:

- identifying and addressing the issues
- identifying factors that show the needs
- identifying who the players are and include them in on the discussion

sickle cell aging population

Ms. Mull noted that clarification and guidelines need to be established.

Ms. Cherry Duckett, Director, Governmental Affairs, UAMS was recognized and stated that Dr. Saccente and Dr. Robin Devan can give a better picture of the sickle cell issues, noting that UAMS along with the Arkansas Minority Health Commission (AMHC) would like to present the sickle cell issue before the Joint Health Committees. Ms. Duckett reported that UAMS has made significant progress with educating local doctors and training them to deal with sickle cell and assisting children that leave Arkansas Children's Hospital (ACH) with making a smooth transition into adulthood by providing them with options of where they can receive treatment. Ms. Mull clarified that the transition age of sickle cell patients at ACH is 21. According to Ms. Duckett, there are issues with the Arkansas Department of Human Services that involve coverage for services. She said sickle cell is a disease that

needs to be managed like any other chronic recurring disease. Ms. Mull stated that there has been some confusion regarding UAMS being considered the primary sickle cell center for patients, noting that there are other doctors, hematologists and internal medicine doctors that are servicing the sickle cell population. According to Ms. Mull, ACH has not defined what UAMS primary role is for sickle cell.

Senator Flowers asked what type of budget does UAMS have in place for the Adult Sickle Cell Clinical Program and what type of budget or costs are anticipated to continue with efforts. Ms. Duckett replied there is no budget—the clinic is being funded through UAMS clinical operations. In addition, UAMS has received resources on a cycle to cycle basis from AMHC and some General Improvement Funds were received in the past, however, no improvement funds were appropriated during the last legislative session. Ms. Duckett said the budget would be a healthy six digit figure and is more manageable with collaboration and cooperation that is being done with other programs within UAMS. Ms. Mull reiterated that there is no commonality and a major issue involves determining where the resources are located. Dr. Mattox noted that AMHC committed \$100,000 for three years.

Dr. Mattox received confirmation regarding the questions that Senator Flowers asked that included:

- amount of funds it would cost to move forward with the expansion of the clinic hours,
- database of community resources,
- development of patient advisory committee; and the
- creation of a statewide physician network its continuation

Senator Flowers said the aforementioned areas are necessary and needed. Dr. Mattox is interested in making sure Arkansas Foundation for Medical Care (AFMC) is incorporating everything Senator Flowers suggested.

Ms. Benton gave a brief overview of how the telemedicine/interactive video is used in hospitals and healthcare providers throughout the state. She explained the interactive video network (IVN) connection allows individuals to deliver and communicate messages face-to-face across the state. Ms. Benton noted that all higher education facilities and community colleges are connected. She stated that in 2010, ANGELS, with the support of UAMS, received a \$102 million grant from the Department of Commerce to provide the interactive video infrastructure that connects every hospital in the state. Approximately 85% of community health centers (CHC's) and 100% of all county health units are also connected. According to Ms. Benton, Dr. Devan does quarterly conferences using this platform to facilitate an education session regarding sickle cell disease. Eventually, advancement in technology will allow primary care providers the capability to access and utilize IVN via Smartphone or iPad on a secure network. Ms. Benton noted that ANGELS also provides prenatal diagnosis and counseling for pregnant women that carry the sickle cell trait.

With regards to reaching physicians in the state, Ms. Richardson said six quarterly conferences have been done so far to reach them. Based on a survey, 60 primary care doctors indicated that they were interested in being contacted. Ms. Mull stated that the Affordable Care Act has helped the sickle cell population afford health care. Senator Flowers asked whether the sickle cell disease and individuals that suffer from any stages of sickle cell are covered under traditional Medicaid. Dr. Saccente replied, pediatric patients are 100% Medicaid eligible if they meet the financial requirements, noting there is a high percent of adults that are eligible but not at 100%. Some of the traditional Medicaid eligibility has decreased for patients that are above the age of 18 and these patients are transitioned to other options. Dr. Saccente is not sure as to what the Medicaid rules are for these patients.

The task force briefly discussed the disconnect that some colleges have regarding the IDEA component. Senator Flowers asked is the sickle cell disease recognized under the Individuals with Disabilities Education Act (IDEA). Mr. Johnson stated that his conversation with Americans with Disabilities Act (ADA) college coordinators is that sickle cell is not recognized under IDEA. He said this dialogue needs to be explored on a continuous basis with shareholders and stakeholders being at the table to

understand what the needs are. Dr. Saccente confirmed that the special education disability category under IDEA does not list sickle cell disease.

Dr. Mattox suggested the task force have sickle cell awareness campaigns that will target individuals with sickle cell disease. Ms. Richardson reported that ANGELS has outreach efforts and does health fairs to educate the public about sickle cell disease and every regional health department administrator is aware that ANGELS exists and they can pass this information on to clients. Ms. Benton said a platform can be utilized to deliver sickle cell disease information via IVN to individuals at higher education facilities and community colleges. Ms. Duckett suggested the task force draft a document with pertinent verbiage to distribute to Dr. Powell, Director, Arkansas Department of Higher Education. She is confident that Dr. Powell would be willing to assist the task force with finding a pathway to communicate information to educate 2-year and 4-year universities regarding sickle cell disease and other related issues and concerns. Senator Flowers appointed Ms. Mull as the lead person to begin working with other individuals on a draft document that will be submitted to Dr. Powell. She also recommended that Ms. Mull and Dr. Mattox work together to create a sickle cell education awareness campaign.

Announcements

Ms. Duckett announced that UAMS has a DVD entitled, "A Day in the Life Of", that is available on the website. Ms. Mull announced that a sickle cell disease information session radio broadcast will be held September 19 on radio station 102.9 at 10:00 am. Dr. Mattox noted that AMHC welcomes feedback from the task force regarding the types of images and information distributed. In addition, she extended an invitation to the task force to attend events at Historical Black Colleges to disseminate information and educate the community regarding sickle cell and the opportunities that are available.

Senator Flowers asked that Dr. Selig or his designee be invited to the next task force meeting.

Next Meeting Date

The task force agreed to meet quarterly on Mondays. The next tentative meeting will be held Monday, October 5, 2015 at 10:30 a.m. in Room 130 of the State Capitol.

Next Meeting Agenda Items

- Discussion with Mr. Ron Selig – Arkansas Department of Human Services
- Discussion with Dr. Brett Powell – Arkansas Department of Higher Education
- Discussion with Dr. Robin Devan – UAMS

With no further business, the committees adjourned at 12:00 PM.